## **INTEGRATION COMMENTS FOR MS:**

Thank you for the opportunity to comment on this most important undertaking. I am Linda Wilkinson, the Director of community Development Education for the Central Virginia Chapter of the National MS Society. I am representing the four NMSS Chapters serving Virginia. **Multiple Sclerosis (MS)** is a chronic, life-long, and often disabling disease of the central nervous system that is usually diagnosed in adults between the ages of 20-50. Symptoms can include debilitating fatigue, blurry vision, mobility difficulties and cognitive problems, and often come and go without warning or pattern.

Four chapters of the National Multiple Sclerosis Society serve Virginians living with multiple sclerosis. They include the Blue Ridge, Central Virginia, Hampton Roads and National Capital chapters. These chapters collaborate to address the advocacy needs of their members through the **Multiple Sclerosis Virginia Consumer Action Network (MS VA CAN)**. The MS VA CAN represents over 10,000 Virginians living with MS although there are likely many more Virginians living with MS than that number represents. Since MS is a disease that affects the entire family, we estimate the representation of MS VA CAN at approximately 30,000 *Virginians*. Furthermore, people with MS share physical and sensory disabilities, and therefore heath care concerns and legislation, of several other groups such as arthritis, spinal cord injury and vision impairment.

Improving the coordination of care and services through efforts to establish an integrated approach is viewed as critically important to those with MS and their caregivers. Viewing care as a comprehensive system aimed at the individual's unique situation can be a more efficient, effective and caring model than the fragmented system of care providers that patients see today. It is a patient-oriented model for healthcare that puts people at the center, rather than funding-oriented system that puts the funding bureaucracy as the center of focus.

As you look at community-based integrated care, the NMSS asks that you have as a tenet of the model the utilization of community-based organizations with proven track records working with the various populations including those with MS. People with MS and their caregivers look to us for information, referral and support. We work with them everyday and have strong relationships. We would ask that the support

services we provide and refer clients to be integral to the systems developed. We see everyday that access to care (including medications), mobility and good nutrition are essential to sustaining good health and allowing people with MS to remain as productive as possible. Patient options and access to choice is important a patient-center system.

We would ask that you recognize these realities in the structure of the benefits or financial incentives offered if you proceed with enhanced benefit account plans. It is vital that individuals have supporting services (transportation to healthcare, nutrition, emergency access through a telephone, etc.). Therefore, we would ask that these tools and services be considered and included for patients enrolled in such integrated care and flexible plans.

If the decision is made to consider special needs populations with chronic conditions, such as MS, and integrated plans for these patients, we would ask that integration of support services as well as utilization of community-based providers who work with these same patients be included. Virginia has many such service providers who work at the community level and these are services that are vital to maintaining the health of people with MS. Community resources across the Commonwealth are varied and each MS patient's needs are different and we work with many to help them mix and match the services available across what seems to them to be a fragmented system of care. Community-based coordination needs to be considered for plan requirements.

Again, thank you for this opportunity to offer our comments the NMSS supports your efforts for improved system integration and offer to participate as appropriate in these efforts.